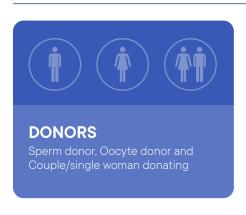
Good practice recommendations for information provision for those involved in reproductive donation



Medically Assisted Reproduction centres and gamete banks should have in place resources and training to ensure the relevant staff groups are available and can provide informed support

Who needs information and support?









Direct-to-consumer genetic testing People submit DNA to find information about their origin. Testing can:

→ Reveal the lack of a genetic link between the social parent and the offspring

Reveal that a family member has donated gametes/embryos

Identify genetic relatives (donor, siblings, family members)



Key information and support to be offered, in general and in consideration of the availability of direct-to-consumer genetic testing and matching services

> CHECKLISTS on information provision to donors, recipients and offspring

Checklist on information and support to be offered to donors







BEFORE DONATION OF GAMETES OR EMBRYOS				
INFORMATION PROVISION				
HEALTH AND RISKS	Relevant national legislation governing the donation; explain that: - Legislation may change prospectively and retrospectively - Legislation may vary between countries			
	Donation is voluntary, but a reimbursement/compensation may be allowed			
	Information on recorded personal/medical data; explain: – Who can access the data and when (GDPR) – How medical information can be updated/clarified			
	Different options for donation (anonymous, Identity release, known) and what is allowed			
	Donor quota (or the lack thereof); explain possible consequences			
	Duration of storage; explain possible consequences (with regards to age differences)			
	The option for the donor to include his/her own restrictions with regards to the donation (number of families, type of recipients, post-mortem use) or withdraw his/her consent			
	Voluntary/mandatory donor registries and direct-to-consumer genetic testing; explain the implications			
	Medical (genetic) screening and follow-up			
	Risks of donating (mainly for oocyte donors)			
	The possibility of being contacted by the MAR centre/gamete bank for additional medical information, such as unexpected diseases in the offspring			
COUNSELLING				
Counselling should be available before, during and after donation				
PRIOR TO CONTACT WITH OFFSPRING				
Counselling should be available before, during and after contact with offspring				

Checklist on information and support to be offered to recipients









BEFORE USING DONATED GAMETES				
INFORMATION PROVISION				
LEGISLATION	Relevant national legislation governing the donation; explain that: - Legislation may change prospectively and retrospectively - Legislation may vary between countries			
	Information on recorded personal/medical data; explain: – Who can access the data and when (GDPR) – How medical information can be updated/clarified			
	Different options for donation (anonymous, Identity release, known) and what is allowed			
	Donor quota (or the lack thereof); explain possible consequences			
	Duration of storage; explain possible consequences (with regards to age differences)			
	The option for the donor to include his/her own restrictions with regards to the donation (number of families, type of recipients, post-mortem use) or withdraw his/her consent. Also include the impact on possibility of genetic (half-) siblings			
	Voluntary/mandatory donor registries and direct-to-consumer genetic testing; explain the implications			
HEALTH & RISKS	Benefits and (medical/obstetric) risks			
SIGNPOSTING to resources, including literature (books), websites, peer support groups, dedicated counsellors and/or organisations				
COUNSELLING				
Counselling should be available before, during and after using donated gametes. It should include: - Implications of using donor gametes - How to handle questions from family/friends - Disclosure, why and how				

Checklist on information and support to be offered to offspring







CONTACT WITH THE CENTRE FOR INFORMATION/SUPPORT			
INFORMATION PROVISION AND SUPPORT			
Type and content of information they can access from the authorities / MAR centre: - This information may not match their expectations - The information may have changed since the donation - Requesting information does not imply that one should contact the donor			
Donor registries and how they function			
Relevant national legislation governing the donation. Explain that this: – May change prospectively and retrospectively – May vary between countries			
Donor quota (or the lack thereof) + possible consequences			
SIGNPOSTING to resources, including literature (books), websites, peer support groups, dedicated counsellors and/or organisations			
COUNSELLING			
Counselling should be available, and include: - Implications of revealing to others their donor conception - How to deal with unwanted questioning/ judgements - Revealing donor conception is irreversible			
SEARCHING FOR THE DONOR (or same-donor offspring)			
INFORMATION PROVISION			
The donor may not expect to be contacted and may not be prepared (through counselling)			
The donor may not be open to contact or may not have the same expectations			
Contacting the donor is not always a positive experience			
Same-donor offspring could be found, or not			
Revealing your identity is irreversible			
Similarities between you and the donor/same-donor offspring may exist, or not			
Meeting the donor/same-donor offspring does not guarantee a good relationship			
COUNSELLING			
Counselling should be available, and include: - Expectations with regards to contact with the donor or same-donor offspring and how to include them in one's personal life - Consequences of (not) telling parents and relatives			